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ABSTRACT

This executive summary briefly presents the results of an evaluation of the Centers for Independent Living Program, required by the 1984 amendments to the Rehabilitation Act of 1973, Part B. The evaluation, which assessed the impact of the centers in increasing opportunities for disabled individuals, was based upon data acquired through: mail surveys of 156 centers funded in 1984-85; 2,700 disabled consumers of center services, and 180 local community agencies; and on-site interviews with consumers, center staff, and community agency representatives at 40 centers. Evaluation findings are summarized regarding: the number and type of handicapped individuals served; the extent to which handicapped persons are served; the types of services provided; funding sources; the percentage of resources committed to each type of service; how services provided contribute to the maintenance of or the increased independence of handicapped individuals served; extent to which handicapped individuals participate in the management of and decision making of the center; the extent of capacity-building activities including collaboration with other agencies and organizations; the extent of catalytic activities to promote community awareness, involvement, and assistance; the extent and impact of outreach activities; center management practices; and factors contributing to success. It is concluded that the Centers for Independent Living Program is successfully helping large numbers of disabled citizens maintain or improve their ability to live independently in their communities. (CB)

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COMPREHENSIVE EVALUATION OF THE TITLE VII, PART B, OF THE REHABILITATION ACT AS AMENDED, CENTERS FOR INDEPENDENT LIVING PROGRAM

EXECUTIVE SUMMARY

INTRODUCTION AND STUDY APPROACH

The 1984 amendments to the Rehabilitation Act required a comprehensive evaluation of the Title VII, Part B of the Rehabilitation Act of 1973 Centers for Independent Living Program. The purpose of the program is to provide independent living services to persons with disabilities and their families to increase options for such persons to live independently in the community, to improve the quality of life for disabled individuals and to maximize their integration into the mainstream of society, and whenever possible, to contribute to the vocational outcomes and gains that vocational rehabilitation (VR) services seek to achieve.

During the first phase of the evaluation, measures -- or "standards" -- were developed to reflect 11 specific areas of interest to Congress. The process for developing the evaluation standards ensured broad input from centers for independent living, consumer advocacy organizations, researchers, and policy makers. The evaluation standards then were approved by the National Council on the Handicapped for use in the evaluation. In addition to their role in the national evaluation, the standards were also designed to serve as a self-evaluation tool for the centers.

This report describes the evaluation's key findings. The study draws upon data acquired through: a mail survey of all 156 Part-B-funded centers, to which 121 centers responded; on-site interviews with center staff, consumers, and community agency representatives at 40 sample sites; a mail survey of 2,700 consumers selected from 36 sample centers, to which 1,030 consumers responded; and a mail survey of 180 local community agencies, to which 100 agencies responded. Findings presented are based on analysis of survey respondents.

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Study findings primarily reflect data from the 1984-85 project year, during which the 156 centers received Part B funds totaling $21 million, at a average award of $134,600. The average Part B funding for the 121 responding centers was $133,900 with a median of $130,000. Overall, the centers can be described as consumer-oriented organizations, focusing on community changes as well as individual client services. Their primary goals are to increase independent living options for individuals with disabilities, and to promote the maximum integration and participation of this population in society.

State vocational rehabilitation (VR) agencies act as the Part B grantee for 79% of the 121 centers responding to the survey, generally subcontracting to local community organizations to provide services (69%), although a few VR agencies operate independent living programs themselves (10% of the centers are located within VR agencies). The remaining 21% of the centers (25 centers) received funds directly from the federal government.

SUMMARY OF FINDINGS RELATED TO SECTION 711(c)(3) REQUIREMENTS

"(A) the number and types of handicapped individuals assisted" and "(B) the extent to which individuals with varying handicapping conditions were served"

The 121 centers responding to the survey (78% of all Part B centers) reported serving more than 48,000 persons with disabilities during 1984-85, as well as 14,000 nondisabled individuals (family and friends). These centers reported that nearly 56,000 additional individuals received information and referral assistance.

The Title VII Part B centers provided services to a population with a wide range of disabilities. As estimated, 75% of the 990 consumers responding to the survey were severely disabled (as defined by receipt of SSI, total blindness, or use of attendant care). Individuals with orthopedic disabilities were the largest group served (24,000 or about 48%); followed by persons with hearing impairments (8,100 or about 17%); "other" disabilities (7,400 or about 15%), including diabetes, epilepsy, stroke, and head injuries; and visual impairments (5,700 or about 12%). Mental illness and

mental retardation were the categories least frequently reported, together comprising only 8% of the consumer population (about 3,900). Two-thirds of the 121 centers served at least five of the six major disability groups, while only 11% (13 centers) reportedly served a single disability group. These latter centers were funded specifically to serve individuals with visual impairments.

"(C) the types of services provided"

The Title VII Part B centers provided a wide range of independent living support services. Almost all of the 121 responding centers provided the services specified in the evaluation standards -- advocacy, independent living skills training, peer counseling, and information and referral. Most centers offered a wide range of other types of assistance to facilitate consumer goal achievement, including services related to housing, attendant/homemaker assistance, transportation, equipment, and social/recreational activities. A majority of the centers also provided other types of non-peer counseling, and communication assistance such as interpreter and reader services. Finally, over one-third of the centers provided vocational, educational, and family support services.

"(D) sources of funding" and "(E) the percentage of resources committed to each type of service"

The responding centers' total annual budgets (N=111) ranged from $43,000 to $1.3 million, with a median of $240,000 and an average of $323,000, of which the Part B share was about 44%. The second largest source of funds was state monies, received by 67 (57%) of the centers and comprising approximately 24% of the centers' total program funding. Almost half (58) of the centers received funding from private sources, which comprised about 8% of overall center budgets. Other federal funds and local funds accounted for a very small portion of the centers' budgets (each less than 6%). The longer

centers were in operation, the less heavily they tended to rely on Part B funds.

Centers devoted an average of one-fourth of their resources to community change and capacity-building activities, with the remaining three-fourths allocated to direct client services. The cost per consumer receiving direct services averaged $435 annually, of which $191 was provided by Part B.

"(F) how services provided contribute to the maintenance of or the increased independence of handicapped individuals assisted"

Unlike vocational rehabilitation programs with a focus on employment outcomes, the independent living centers do not have a single goal or measure of success. Rather, they respond to a wide range of particular needs and goals expressed by their consumers, ranging from housing and attendant care to enhanced self-direction and personal growth. Thus, the assessment of program effectiveness must include a wide range of measures.

The 121 responding centers reported that their efforts contributed to raising more than $7.5 million in additional funding for attendant care, adding over 3,000 qualified attendants to local attendant pools, and helping 5,000 individuals secure attendants; making more than 1,800 housing units accessible, and helping 2,250 people improve their housing accessibility; developing over 1,000 jobs, and helping 1,150 individuals secure jobs; making over 2,300 ramps and curb cuts, and helping 2,000 people move to less restrictive environments. These types of community changes are directly related to disabled individuals achieving equal access to society as well as their ability to either achieve or maintain an independent lifestyle.

The responding centers reported a total of 58,000 positive individual consumer outcomes achieved. Consumers' self-reports of outcomes were even higher. Over three-fourths of the 990 consumer respondents achieved at least one improvement in housing, income, transportation, education, or employment situation. Almost 90% (880 consumers) reported an outcome in at least one of the following areas: personal/social change; acquiring adaptive aids, bene-

fits, and/or services; developing skills; and acquiring knowledge associated with living more independently. Over 90% (n=906) reported either a situational improvement or some other type of gain.

Statistical analyses showed that positive outcomes were more consistently associated with the types and amount of services received than with center organizational factors or individual consumer characteristics, and that center services had contributed substantially to consumer gains in independent living. Moreover, about half (n=467) of the consumer survey respondents directly attributed the improvements they had achieved to help they received from a center.

"(G) extent to which handicapped individuals participate in the management and decision-making in the center"

A majority of the 121 responding centers had a disabled director, 55% (66 centers) had Boards with a majority of disabled members, and on average 51% of center staff had disabilities. The community agencies surveyed confirmed that involvement of disabled individuals in center policy direction and management was emphasized by most centers.

Thirty-two percent (318) of the consumers surveyed reported some kind of involvement in center operations, including serving on a Board of Directors or an advisory committee, working as paid or volunteer staff, or evaluating services. Consumers rated the centers as highly effective in involving disabled individuals in running the center.

However, among the centers there were a substantial number that exhibited less participation of individuals with disabilities. In almost 30% of the 121 responding centers, less than a fifth of the board members had disabilities. Most of these centers operated within an umbrella organization. While disabled individuals in these centers frequently were involved in staff roles, they were much less likely to be involved in policy direction and management roles.

"(H) the extent of capacity-building activities including collaboration with other agencies and organizations" and "(I) the extent of catalytic activities to promote community awareness, involvement, and assistance"

Study findings indicated that the 121 responding centers were involved extensively in capacity-building activities, including collaboration with a wide range of other community and public organizations. A majority of the centers reported that they had provided information to other agencies working with persons with disabilities. Nearly two-thirds of the 100 responding community agencies reported receiving information and technical assistance from centers; 75% of these agencies referred consumers to centers, and over half had cooperated with centers in service provision and advocacy.

The centers' reports of their community development efforts were confirmed by the community agency responses, which indicated that centers had substantially expanded personal care and transportation options, and had promoted disability awareness in the community. Over half (55) of the community agencies also reported that contact with a center led to an increase in their own efforts to improve community options for persons with disabilities.

Finally, almost three-fourths of the 100 responding community agencies rated the centers as very good or outstanding advocates in their communities. Centers that allocated more resources to community efforts and that involved more consumers in the management and operation of the center were more likely to have greater community impacts.

"(J) extent of outreach efforts and the impact of such efforts"

For centers serving rural areas, outreach often involves staff efforts to reach consumers' homes in order to bridge the distances and physical access barriers associated with rural living for people with disabilities. For urban areas, outreach more often refers to publicity efforts and cultivating contacts with private and public community agencies and professionals to ensure their referral of disabled individuals to the center. The results

of center outreach efforts were reflected in the consumer survey responses -- 62% of the 945 consumers responding reported they had learned about the center from other agencies, 15% had heard of the center directly from center staff and publicity, and 23% learned by word of mouth from other consumers. While the impact of outreach is difficult to assess, the disability distribution of consumers served by centers is similar to that of the nation as a whole.

OTHER MAJOR FINDINGS

Center Management Practices

Centers within umbrella agencies tended to have more sophisticated management practices, and generally had adopted the procedures of the parent agency, or simply had the umbrella administration conduct certain activities for them. While most of the 121 responding centers collected data appropriate for assessing performance, the data were not always readily retrievable or comparable because of the lack of standardized service definitions and outcome measures. This was particularly true among smaller centers with limited resources, centers that were not required to report such data on an ongoing basis to funding agencies, and those whose records had not been computerized.

Factors Contributing to Success

Analyses were conducted of the effect of service, organizational, and consumer characteristics on consumer outcomes. The most significant factors influencing consumers' success were the service characteristics. These included the types of services received, the overall amount of service, the consumer's personal and continued contact with the center over time, the use of central case managers, and the provision of peer role models to consumers via contact with disabled staff, and all contributed to consumer outcomes, regardless of the consumer's characteristics. The centers that reported higher outcomes were those with higher percentages of staff with disabili-

ties, higher percentages of funding from nonfederal sources, and those that received their funding directly from the federal government. The consumers who reported higher outcomes tended to be younger, had disabilities other than mental retardation, were (or had previously been) VR clients, and lived in supervised settings.

Conclusion

The Title VII Part B Centers for Independent Living Program is successfully helping large numbers of disabled citizens maintain or improve their ability to live independently in their communities. They accomplish this through individual and direct services, referral to other resources, and activities targeted towards community change. There remains much diversity among centers in targeted client populations, services offered, management practices and systems in place, and involvement of individuals with disabilities in center planning and management. Some of this diversity is an appropriate response to variation in local needs. However, it also appears that many centers would benefit from increased guidance and technical assistance, greater information exchange with other centers, and increased levels or stability of funding. Also, the centers collect a wealth of information about their services and the consumers they serve that could be more valuable to program planners and policy makers if definitions and measures were uniform across centers.